

Maternal and Child Health Bureau, Health Resources and Services Administration  
U.S. Department of Health and Human Services  
5600 Fishers Lane  
Rockville, MD 20857

Re: Request for Information: A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and Families

To Whom It May Concern:

[The Inclusion Subcommittee of the Integration and Alignment Committee of the Illinois Early Learning Council](#) is appreciative of the opportunity to offer information to the Maternal and Child Health Bureau (MCHB) on A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and Families. As a body of the Illinois Early Learning Council, a public-private partnership created by [Public Act 93-380](#) and dedicated to strengthening programs and services for children birth to age five in Illinois, the Inclusion Subcommittee specifically works to ensure integration and alignment of early childhood programs and initiatives to other systems in issues related to children with or at risk of delays and disabilities.

The Inclusion Subcommittee recognizes that substantial efforts have already been undertaken to consult with a select group of families of CYSHCN and experts to identify priorities to improve outcomes across systems of care. Below, we offer additional suggestions to strengthen the Blueprint through an early childhood lens.

**I. Are there items that are missing from the draft goals and objectives?**

Though cross-systems coordination and the comprehensive well-being of CYSHCN are clearly elevated throughout the Blueprint, the Inclusion Subcommittee would encourage MCHB to consider the importance of the early childhood care and education system. Children with special health care needs will touch different systems over time, at different developmental stages. Resources aimed at supporting the very youngest children, including infant and early childhood mental health consultation for providers serving infants and toddlers and their families, as well as Early Intervention and Early Childhood Special Education, can be critical to ensuring that CYSHCN also receive referrals to local services and community-based agencies.

Similarly, recognizing the importance of developmentally appropriate, high-quality childcare for all children, including CYSHCN, the Subcommittee would additionally elevate the need to provide assistance to child care providers, through grants or other financial supports, to ensure that families can access early childhood programs that support the well-being of children with special health care needs. This should also extend to respite care to allow parents with CYSHCN to participate in the mental health & self-care resources mentioned in the [Blueprint](#). Financial supports could be provided to child care providers to modify a child care setting to accommodate children with diverse abilities and needs (building ramps, widening doors, etc.), purchase items such as sensory equipment or computer equipment and software for children with special health care needs, or pay Early Intervention and Early Childhood Special Education providers for collaboration time with child care providers regardless of where child receives services.

**II. What steps need to be taken to implement these goals at the community, state and federal levels?**

The Inclusion Subcommittee appreciates that MCHB has specifically articulated the need to improve health equity with a specific focus on meeting the needs of subgroups of CYSHCN that are most vulnerable, including those in foster care, those in urban and rural settings, and those at a higher risk of mental and behavioral health issues. Creative, multi-system approaches are necessary to overcome the intersecting barriers faced by families of CYSHCN in accessing quality care. For example, to improve access to services for families in rural areas, health systems may need to offer financial assistance to overcome transit limitations to attend regular appointments, while also incentivizing the recruitment of specialists in rural areas to remedy supply-side issues. To ensure that community, state, and federal implementors share a common understanding of the vulnerable communities of CYSHCN that may require additional attention, MCHB should adopt a priority populations framework to name and define these specific subgroups. In 2019, the Illinois Early Learning Council adopted an [updated list of priority populations](#) to improve access to early learning programs for the highest need children and families, and increase awareness of the unique barriers faced by underrepresented and underserved populations. The Inclusion Subcommittee would elevate this example as a possible tool for strengthening implementation of MCHB's health equity objectives for CYSHCN.

Additionally, the Inclusion Subcommittee would note the need to raise awareness of the major objectives in the Blueprint, as advocacy will be necessary to sustain the systems changes represented by the objectives enumerated by MCHB. Noting the first objective under the key area of health equity, "structural and systemic policies that further inequalities are replaced. Policies and programs recognize and address the barriers to health equity: poverty and discrimination and their downstream consequences," the Subcommittee would encourage MCHB to invest in communications strategies to articulate to advocates for CYSHCN how to identify existing barriers, and further support coordinated advocacy.

### **III. How should families, providers and other key programs and systems be involved in the implementation of the goals and objectives outlined in the Blueprint?**

The Inclusion Subcommittee appreciates that the Blueprint specifically names CYSHCN and families as partners in decision making with professionals in a number of goals. Beyond viewing families as partners, the Inclusion Subcommittee would encourage MCHB to add language to the Blueprint that emphasizes that parents and CYSHCN are uniquely positioned as experts in their own lived experiences, and must be valued as the primary drivers across all systems of supports. Embracing the families of CYSHCN as experts requires a cultural shift that can be elevated through the Blueprint but must ultimately be taken up by stakeholders across health, education, and other family facing systems. Training and support for the workforce, including pre-service and in-service professional development, should not only emphasize family and child well-being but should also set the tone for empowering families to drive decisions for their CYSHCN and should make it clear that the relationship between providers and families is not adversarial.

Noting where in the Blueprint MCHB has emphasized the need for improved public health data systems and improved public health surveillance and health equity outcomes, the Inclusion Subcommittee would also advocate for an increased attention to family privacy concerns. While cross-silo information sharing and collaboration are absolutely necessary to improve outcomes for CYSHCN, families are often the only constant across different service systems. In certain instances, data privacy can offer a protective barrier to families and ensure that parent and guardians' understanding of their child's needs are fully considered by health and other providers.

Even with a priority populations framework that elevates the shared barriers for underserved communities, one-size fits all approaches still pose barriers to health equity. The Inclusion

Subcommittee would encourage MCHB to leverage the resources and engagement networks of existing early learning providers (both center- and home-based) and early childhood collaborations in local communities to establish bi-directional pathways for communication with the families of CYSHCN. Further drawing from the early childhood field, we would elevate the potential applicability of the [Facilitating Attuned Interactions approach \(FAN\)](#), which aims to strengthen the provider-parent relationship to support parents' connection to their children. Though created as a tool [for infant specialists](#) working with parents struggling with their infants' crying, feeding or sleeping, the FAN approach can also support relationship building in other settings, and can be an important framework for family-facing providers. The Inclusion Subcommittee would elevate this tool to support building out the cross-system capacity of professional providers to connect with and establish meaningful communication pathways with parents, which in turn can inform implementation of the goals outlined within the Blueprint.

**IV. What additional research, policy and programmatic work should be consulted and considered as the Blueprint is finalized?**

Many professionals serving CYSHCN may not have significant lived experience working with children with developmental delays or disabilities or special health care needs until they enter a clinical setting. To support the Blueprint's aim to ensure that "workforce supporting CYSHCN and families are well-trained, culturally competent, accessible, and reflects the families they serve," the Subcommittee would encourage MCHB to consider the interdisciplinary training approaches of the Illinois [Leadership Education in Neurodevelopmental and related Disabilities \(LEND\) Program](#). The LEND program, which provides long-term, graduate level interdisciplinary training for professionals supporting the health and wellbeing of individuals with disabilities, prioritizes family visits to offer trainees insights into the daily experiences of families of children with disabilities. Similarly, the Master's of Education in Early Childhood Special Education program at Elmhurst University requires students to spend time in the homes of CYSHCN to ensure that intervention planning and other activities are informed by a deep understanding of families' lived experiences, routines, and needs. These times of immersive training experiences are crucial to ensure the workforce has capacity to support the holistic well-being of CYSHCN and their families.

Thank you for consideration of the above comments. For any additional information, please contact Kayla Goldfarb, Inclusion Subcommittee staffer, Illinois Policy at Start Early, 33 W. Monroe Street, Suite 1200, Chicago, Illinois 60603, [kgoldfarb@startearly.org](mailto:kgoldfarb@startearly.org)

Sincerely,

Inclusion Subcommittee, Illinois Early Learning Council